

3/16/12

Hearing re Section 19-13-D4b of the Regulations of the Connecticut State Agencies

Based on my years as a physician referring patients for inpatient Hospice care, and my personal experience with my wife's stay at the Connecticut Hospice, I feel that the proposed change is unwise, in that it opens the door for reducing the standards for staff and facilities for inpatient Hospice care. I believe that my personal experience may be most useful for your consideration of this issue.

My late wife, Susan W. Wolfson, was an inpatient at the Yale-New Haven Hospital 7 years ago, after a long and gallant fight with ovarian cancer. She had willingly and cheerfully undergone 3 major abdominal operations for this cancer, had lived through too many runs of chemotherapy to count. But now she was confined to bed, with a broken right arm sustained in a fall, intestinal obstruction, and large tumor masses filling her abdomen and pressing on the nerves to her right leg. She could not eat. Her stomach contents were being continuously suctioned, and she was in constant pain.

Her surgeon suggested that she might benefit from more surgery, and her reply was "How about Hospice". She was transferred the next day, and we lived through a miraculous change. She was seen immediately by a team of physicians, nurses, social workers, and pharmacists. Her intravenous pain medications were adjusted, and within one half an hour, she was free of pain. Sent to Hospice for help with dying, she came to life.

Two hours later, holding hands, we attended a concert, in the common room on the floor. Over the next days, we were able to wheel her bed out of doors, and she sat in the sun, watching gulls fly over the sound. A physical therapist came by to help her transfer to a commode and even take a few halting steps. A volunteer visited and Sue participated in arts and crafts, using her left hand.

She was thirsty and hungry. She was on continuous suction and so could not eat. But rules at this Hospice are made for the patients! She was told that she could drink-it would be sucked out anyway, and she could have taste, and the feeling of drinking. She started with apple juice and then begged for chicken soup. Our friends participated in a "cook out," competing for the most flavorful chicken broth. I am forbidden to reveal the winner of this contest.

After a week, we were introduced to a new capability. She was placed in a hoist, lifted up, and then lowered into a huge jacuzzi-like bath, for her first bath in months! I sat outside, listening to the 3 aides attending her as they sang songs with her.

My children and I took turns sleeping in a cot by her side. And so we witnessed the nurses and aides making rounds at 2 am. Anyone who was awake was offered, and received, a sponge bath. And then slept.

Each morning, the physicians, nurses and social service team members made rounds to check on each of the patients. The physicians ordered the minor but crucial changes in medications to ensure that patients were free of pain or nausea, but not oversedated. And these changes were instantly put into place by the onsite pharmacists. Those with constant cough, with respiratory distress, with pain, or itching, diarrhea or constipation, received care. None needed to wait hours for changes in their regimen to take place.

As a family, we were supported, listened to, loved by the staff. We met other families there, shared our gratitude for the care our loved ones were receiving. We were allowed to have parties for our families and friends in the common room. And free of pain, alert and awake, Sue was able to say goodbye to all of us.

The day came when the pain returned, with a vengeance. And she needed enough medication so that she slept. Three days later, I helped the staff give her a bath at 2 am. And they saw signs that the end was near. I called my children. We sat with her. And her last breath came as the sun rose, over the Sound.

I hope that you all understand that patients who need inpatient Hospice care, like my wife, need what can only be described as intensive care. With this care, many can have peaceful, hopeful, even mirthful days, as they are dying.

The staff levels contained in the current Regulations are totally appropriate, and should be met by any facility that undertakes the care of terminally ill patients -to repeat, this is intensive care. Thank you for listening.

Steven Wolfson, MD